

# **THE LEGISLATIVE BLUE RIBBON COMMISSION ON AUTISM: Task Force on Early Identification & Intervention**

## **Summary of Findings & Recommendations**

The Early Identification and Intervention Task Force (EITF) held three public meetings. A total of 45 individuals (list attached) attended these day-long sessions (10AM-3PM.) Additional members of the public participated by teleconference access. Eleven of the task force participants (24%) were parents of individuals with autism spectrum disorders (ASD.) The EITF represented the following areas of expertise and/or affiliations: early intervention for ASD (15 individuals); early education (9); state department or agency (7); non-profit or foundation (7); legislative staff (7); healthcare professional (6); academia or research (6); regional center or DDS (6); local or county programs (5). Attendance was excellent with 29 of the participants (64%) attending at least two of the sessions; fourteen members (31%) were present at all of the meetings.

The following summary provides a broad overview of the EITF's work. Detailed information (i.e. agendas, meeting notes, specific recommendations; background information) for each of the meetings will be provided as separate attachments.

The initial meeting (Nov. 14, 2006) was attended by 31 participants. Dr. Barbara Firestone provided welcoming remarks, introductions, a review of the Autism Commission, as well as leading a discussion on the goals, objectives, timelines of the EITF and the importance of this group in assisting and guiding the Autism Commission. Subsequently, the EITF reviewed the existing systems of care for ASD by the following categories: state funded programs; regional centers; public education; Kaiser Healthcare; private health plans. The group engaged in extensive discussions and deliberations on the strengths and gaps of these existing systems. The meeting concluded with the EITF identifying and prioritizing problems that were deemed most important for future actions.

The second meeting (Dec. 13, 2006) was attended by 31 participants. The EITF established that the most significant barriers to the early identification of ASD were the following: lack of effective developmental screening; problems in transitioning from regional centers to preschool programs at 3 years of age; lack of services to underserved communities; lack of community outreach and public information. The EITF also identified that the major obstacles to early intervention were as follows: inconsistent quality of care; inadequate teacher training and preparation; fragmented systems of care; inadequate information on "best practice" standards and outcome measures. The participants then assembled in four small workgroups to discuss on provide solutions to these existing gaps. The EITF then reconvened to discuss the workgroups' specific recommendations as well as to deliberate the following:

- Were the gaps, barriers and problems adequately defined and what is the state's role in addressing these issues?
- What are specific strategies to close these gaps and have these recommendations considered such issues resource allocation; feasibility of change; outcome measurements; potential for systemic changes that could benefit a larger population of children.

- Importance of identifying existing systems that are effective and successful models.
- Importance of addressing factors related to diversity, equity & cultural competence.
- Importance of identifying/engaging stakeholders, experts, & additional collaborators.

The final meeting was attended by 28 participants. The group concurred that there were four gaps, all of major importance, which should be addressed by the Autism Commission. Further, the EITF noted that professional development was a critical and important overarching issue that impacted all of these priority “gaps.” These issues, not prioritized in order of importance, included the following:

1. Transition from regional centers to school districts at 3 years of age:  
The frequent lack of continuity in the programs and services when children with ASD transition from Early Start, and/or regional center services, to programs/services provided by school districts.
2. Helping parents to better access, utilize, & navigate complex systems of care:  
The existing systems of care for ASD are extremely complex and pose challenges to parents, family members and childcare providers in terms understanding and navigating these programs and services.
3. Overcoming disparities & inequities in access to services for children with ASD:  
Gaps in existing systems and services may delay and/or exclude the diagnosis/intervention of ASD for certain groups of children.
4. The appropriate screening, assessment, referral & intervention of children with ASD.  
Many children are not being diagnosed with ASD in an appropriate and timely manner since only 23% of pediatricians utilize standard developmental assessment tools and/or instruments in their developmental screening of young children.

The EITF believes that recommendations to address these problem areas will require a comprehensive, multi-faceted, integrated, family-focused, community based approach that are also linked to evidence-based best practices and outcome measures. For example, any effort/recommendation to improve ASD detection must ensure that all children identified with ASD (as well as other developmental differences) are promptly linked to appropriate assessment, referral, and intervention services. These considerations are further complicated by the by the complexities and nuances of ASD systems of care.

Accordingly, the EITF is proposing that the existing gaps should be addressed by an incremental approach that is based on establishing a series of demonstration/model projects for each of the four priority problem areas. The EITF emphasizes that these demonstration sites (once their efficacy is established) should be quickly expanded and replicated to provide universal coverage throughout the state. Prior to implementation, each of these concepts will require extensive input, vetting, clarification, planning and analysis. Therefore, the following recommendations are intended as broad “conceptual frameworks” by which to assist future deliberations and to further promulgate the Commission’s work.

Recommendation #1: To address the gaps related to regional center-school district transition at three years of age, model programs entailing voluntary collaboration between regional centers and school districts would be established to provide seamless, integrated, and comprehensive services for ASD children, and their families, from birth to 5 years of age. Importantly, this proposal would combine and assimilate all funding

and resources into a single “block grant” subsidy for each model program. Regional centers would have the flexibility to extend the Early Start program until age 5, at which time they would also establish the child’s eligibility for further, ongoing, “client-based” services. These model programs would also establish integrated case management, service delivery plan, and outcome measures.

Recommendation #2: To address the gaps of assisting parents and families to better access, understand, and navigate the existing complex systems of care, the EITF recommends establishing a statewide telephone “hotline” (as well as other possible supporting resources and assistance) on ASD systems and services. In addition, this center would be organized to assist with the following: coordination and collaboration with regional and local resources and systems of care such as family resource centers and family empowerment centers; statewide media outreach and information campaign; public-private partnerships to inform families and parents, with particular emphasis in underserved communities, on normal developmental milestones and the warning signs of ASD; parent and family focused web-based site; comprehensive and consistent print based material and resource guides to inform and educate parents/families on ASD-systems of care.

Recommendation #3: To address the gaps related to provide ASD services to underserved communities, the EITF recommends establishing an “ASD ombudsperson” section. This section, would partner with a pre-defined number of regional centers to implement the following initiatives: effective community outreach to underserved communities; culturally/ethnically based training and information parent/family focused advocacy training; establishment of a criteria of “parent-family mentor/coaches” that would qualify for regional center reimbursement/vendorization; to establish a system of culturally/ethnically sensitive individuals &/or organizations that are closely integrated and have established ties to the community that would qualify for regional center reimbursement and vendorization.

Recommendation #4: To address the gaps related to early screening, assessment, referral & intervention the EITF recommends establishing demonstration projects to implement more effective models of care. Basic concepts for models would include the following: a broad-based community-linked effort establishing public-private partnerships; information/education outreach on appropriate childhood developmental milestones; appropriate resources & technical assistance; providing structured “universal screening” for all children; innovative approaches (such as the training & reimbursement of parents and non-medical personnel) to developmental screening, triage, and assessments; linkages to existing early childhood development programs; effective resources, effective referral and intervention for children with ASD and other developmental/learning differences.

In summary, there is irrefutable evidence that the early identification and intervention of children with ASD can be truly “lifesaving” and vastly improve their outcomes and futures. The EITF submits these four recommendations as preliminary but important cornerstones in shaping a vision and forging paths that will improve the lives of so many of these precious children and their families.